Ontario
Advisory Council
on Senior Citizens

A Report on Alzheimer's Disease

February 1985

ONTARIO ADVISORY COUNCIL ON SENIOR CITIZENS

A

REPORT

TO

HONOURABLE RON VAN HORNE

MINISTER FOR SENIOR CITIZENS AFFAIRS

RE

ALZHEIMER'S DISEASE

FEBRUARY, 1986

ONTARIO ADVISORY COUNCIL ON SENIOR CITIZENS

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February, 1986

INTRODUCTION

The following question was raised in a letter of November 5, 1985 from Honourable Ron Van Horne, Minister for Senior Citizens Affairs to Mrs. Ivy St. Lawrence, Chairman of the Ontario Advisory Council on Senior Citizens:

> "...I would very much appreciate receiving Council's advice on a number of topics...(including)
>
> 2. Alzheimer's Disease: What are the needs of Alzheimer's patients and their caregivers? Consideration of these needs would include the support and assistance required by family members and other service providers, respite and day programs for the individuals, as well as appropriate institutional care programs and community support services."

Having consulted with many organisations and individuals Council presented its comments to the Minister in the following report, which includes:

A definition of Alzheimer's disease p. 1-6

Part I -
A review of the identified needs of patients with Alzheimer's Disease; p. 7-11

Part II -
A review of the needs of those providing care for patients with Alzheimer's Disease, including:

A. Families p.12-16

B. Professionals p.16-19

C. Volunteers p.20-21

Part III -
A review of the programs already in place and resources that can be used p.21-25

Part IV -
Recommendations p.25-30

In support of the above material, the following appendices are attached:

Appendix A -	A report on a demonstration project in Ottawa, Ontario which includes a therapeutic daycare program and a home assistance program	p.31-34
B -	An annotated, bibliography of studies and articles examined	p.35-43
C -	A list of individuals and organisations who provided valuable information for this report	p.44-47

DEFINITION OF ALZHEIMER'S DISEASE

First described by Alois Alzheimer in 1907, Alzheimer's disease has no known cause, cure or treatment. It is a progressive, degenerative neurological disease that accounts for up to 75% of all dementia and may last, from onset to death, for up to 14 years.

The progression of the disease is highly idiosyncratic, irreversible and is estimated to affect up to 60,000 people in Ontario, although 75% of all elderly persons never become demented. According to the Canadian Geriatrics Research Association, one family in three in Ontario has a member with Alzheimer's Disease.

Among possible causes of Alzheimer's Disease, the following hypotheses are currently under investigation:

1. Viral or environmental agents

2. Excessive accumulations of aluminum or other toxins

3. A genetic defect or predisposition

4. Age related change in the immune system

Diagnosis, in the initial stages, is difficult and care is required to eliminate other treatable causes of dementia, such as depression and drug toxicity, heart failure, malnutrition, hormonal imbalance, infections and sensory deprivation. Memory, orientation, intellectual function, concentration and judgment become increasingly impaired as the disease progresses through four discernibly different stages from onset to death.

IDENTIFICATION OF STAGE I

During Stage I, close family members or business associates would notice the following changes in the patient's behaviour:

- decreasing attention span and concentration;

- memory loss, which may be brief or transitory at the start, but becomes permanent as the disease progresses;

- recognition by the patient that something is amiss with him/her which may result in depression or anxiety;

- a tendency to wander without purpose for short periods of time;

- reverse sleep rhythm, where the patient becomes active at night but sleeps during the day;

- less energy and drive

- quick to anger

IDENTIFICATION OF STAGE 2

Stage 2 of Alzheimer's Disease can be identified by marked changes in the patient's behaviour. These changes may include:

- personality change in the patient, which may be exemplified in some patients by hostility, increased irritability, aggressive behaviour towards the care-giver; overt anti-social behaviour. Other patients become more gentle and passive.

- speech distortion or "echo speech"
- marked deterioration in personal hygiene and grooming;
- increased wandering;
- foot tapping, tongueing corner of mouth
- increasing tendency to choke while eating
- incapable of making plans and decisions

IDENTIFICATION OF STAGE 3

As the disease moves to this stage the patient is:

- obviously disabled
- more lethargic
- disoriented in time and place
- uncertain how to act
- may misidentify people

- may invent words

- poor recent memory with some preservation of past memories

- great change in behaviour

- greater difficulty in chewing and swallowing food

Stage 3 of Alzheimer's Disease probably requires institutional care for the patient.

The main problem for the care-giver is to identify when and where to institutionalize the patient.

IDENTIFICATION OF STAGE 4

Stage 4 is the terminal stage for the Alzheimer patient. The quality of the patient's life is deteriorating and the main concern is the patient's comfort.

THE PATIENT

- requires assistance with even simple tasks

- is very apathetic
- has distorted perception
- shows frequent nonrecognition of loved ones
- walks in short, quick steps
- has more tone in muscles if pulled (looks like resistance or aggression, but is not)
- requires feeding
- requires constant supervision

FOOTNOTES

1. Melvyn J. Ball, London, 1980
2. Dr. Donald Morison Smith: A Consideration of Statistical Estimates Related to A.D. in Ontario, 1983 (unpublished)
3. Alzheimer's Disease, A Scientific Guide for Health Practitioners, U.S. Department of Health and Human Services
4. A New Look at "Senility", members of the Geriatric Assessment Unit, University Hospital, Saskatoon
5. IBID

PART I

THE NEEDS OF INDIVIDUALS HAVING ALZHEIMER'S DISEASE

Accepting that there are four stages in the disease, the patients' needs change as the disease progresses:

STAGE 1. - PATIENT AT HOME

At the beginning stages of the disease the patient is often aware of an increasing incompetency and becomes distressed and fearful. Among his needs are:

- Access to medical care to ensure a good diagnosis and elimination of treatable senile symptoms that affect brain function, including problems caused by drugs and depression

- Access to a Geriatrician and to a specialised multi-disciplinary assessment team

- A safe and accepting environment, with reassurance about fears

- Daycare, ideally therapeutic, providing stimulation and exercise to prolong Stage I as long as possible
- Appropriate advice regarding legal and financial matters
- Friendly visiting
- Some health care, including foot and dental care
- Tasks to help patient maintain a sense of self-worth
- Reality validation
- A respectful approach from caregivers
- Assessment that includes functional abilities as well as verbal, cognitive and neurological factors
- Supervision while eating to prevent choking
- Optimum environmental climate, compatible with each individual's needs

STAGE II - LOCATION: IDEALLY AT HOME

This stage is usually accompanied by marked personality changes and an increasing tendency to wander. At this point the patient needs:

- Greater assistance with hygiene and increased health supervision
- Protection from own actions, which may include anti-social behaviour and wandering, and may invite abuse
- Greater involvement by the family physician to ensure awareness and case management, including consideration of new drugs to prevent mood swings
- Some personal identification and alarm system should the patient wander
- Re-assessment of changing needs for physical and mental health services
- Continuing daycare, providing stimulation and reality validation for as long as possible.

- If antisocial behaviour increases, care in a special Alzheimer unit may be advisable for that stage of the disease

- Increased supervision of activities, especially eating, drinking and smoking

STAGE III - LOCATION: POSSIBLY AT HOME; LONG-TERM CARE PROBABLY NECESSARY

At this stage of the disease the patient is obviously disabled, becoming more disoriented and with markedly poor recent memory. Needs at this point usually lead to institutionalisation, and include:

- Access to multi-discipline geriatric assessment services

- Accommodation in a respite-care facility at regular intervals if the patient is not in long term care

- Constant review of any restraint practices (drugs or physical devices) that may be necessary

- Appropriately heavier nursing care as functions decrease, with monitoring of food and fluid intake and of bowel and bladder protocol

- If institutionalised, may require segregation in a special unit for safety of self and well being of others

- Time of caregiver to ensure safe and adequate food intake

STAGE IV - LOCATION: LONG TERM OR PALLIATIVE CARE

This is the time when the quality of the patient's life is deteriorating as it moves to a close. The main concern is for the patient's comfort and the needs include:

- Access to appropriately located, designed and engineered facilities, staffed with personnel who are trained and supported to work with demented patients

- Heavy duty nursing to ensure the maximum comfort and quality of life possible as the disease completes its course

- Integration in a ward setting with other seriously ill patients, with constant supervision to maintain maximum quality of life and comfort

PART II

A. THE NEEDS OF THE FAMILY CAREGIVERS

Needs of family care-givers tend to escalate, or compound, rather than change as the family member having Alzheimer's disease experiences the progressive stages of the disease.

The following two quotations, taken from the National Advisory Council on Aging's publication Coping and Helping with Alzheimer's Disease, probably sum up the needs of the family better than any:

> "I wish....someone in the house
> with heart and willingness to
> listen to me...." (p.24)

and from the Wages of Sin, by Lucas Malet,

> "After a time....one lights a
> candle called patience and
> guides one's footsteps by that....
> remembering that you are not
> alone. More than half the
> noblest men and women you meet
> carry such candles." (p.42)

The following practical needs of the family care giver have been identified:

- Assistance and support through the patient's receiving dependable, affordable respite care 3 or 4 times a week in the home, in daycare centres and, with increasing frequency, access to institutional respite care overnight or for longer vacation periods.

- The co-ordinated delivery of a variety of home-care/home-making services, including:
  - visiting homemakers, familiar with the disease and having practical skills
  - support and advice from visiting Public Health and V.O.N. staff and other health professionals
  - assistance with minor home maintenance
  - supplies, at reasonable cost, such as diapers and bedpads

- Flexible combinations of services needed at differing stages of the disease

- Training in basic behaviour management techniques to help lessen stress for family

- Assistance by Co-ordinator of homecare/homemaker services regarding possible sources of financial assistance

- Support from Church and community through friendly visiting, support at times of crises, neighbourly watching and care for the Alzheimer patient. Volunteer respite care so that caregiver can attend church if they wish, is often much appreciated

- Assistance with transportation, to take patient to daycare or appointments

- Reassurance of the ability of volunteers to provide adequate respite care for family member

- Support from family physician, both in caring for the patient and in caring for family members during a prolonged stressful period of their lives

- Counselling to help families resolve feelings of grief, anger, guilt and hostility. This counselling should be available throughout the period of stress over the course of the disease

- Access to self-help groups to share knowledge and empathise with caregiver; to know they are not alone

- Information, both oral and written, regarding the diagnosis, progress and outcome of the disease

- Families in rural areas of the province need more information about the disease and where to locate diagnostic and support services. The Alzheimer's Society, through contact with service clubs, and the Womens' Institute in particular, could be most effective in meeting this need

- Guidance in legal and financial matters, especially issues of guardianship and trusteeship

- Assistance in making the home as safe and secure as possible for the patient and encouragement to provide means of identification, such as the Medic-Alert bracelets, for the patient

- Assistance in making timely application for longterm care which the patient will probably require in Stage III or IV of the disease, and in handling separation trauma

- Increased support and services in final stages awaiting admission

- Access to longterm care for the patient very quickly, once it becomes necessary

- Counselling regarding quality of life for Alzheimer patients, including longterm palliative and terminal care

- Access to hostel facilities near the institution providing longterm care, where visiting families can find rest and support

- To know that research into the disease is ongoing and inroads are being made into causes of the disease

B. THE NEEDS OF PROFESSIONALS AND HEALTH CARE STAFF

The needs of professionals and staff working with Alzheimer patients and their families have been identified as follows:

- Education in the diagnosis, treatment and care of Alzheimer patients

- Continuing in-service counselling and support for all levels of staff working with Alzheimer's patients. In this respect Homemakers need special training and support to look after Alzheimer patients

- Counselling is required related to the degenerative, incurable nature of the disease, with focus on strategies to ensure patients enjoy the maximum stimulation and quality of life possible in all stages of their illness

- Training in behaviour management techniques

- Continuing education programs

- Well developed basic nursing skills are needed by nurses providing heavy duty nursing care to Stage III and IV Alzheimer patients

- <u>All</u> staff working in longterm care facilities need appropriate ongoing in-service training, to enable them to understand the special needs of their older patients and to encourage the development of a supportive team approach among all staff

- Training in recognising abuse of, or by, patients, whether in longterm care facilities or at home

- Higher staff-to-patient ratios are required in units caring for Alzheimer patients

- More time to spend with patients, especially at feeding times

- Institutional staff become attached to longterm residents; they need the opportunity to mourn the eventual death of their patients

- Staff in longterm care facilities need the opportunity to rotate duty, if they wish, between Alzheimer and other patients

- Rightly or wrongly, physicians generally are seen as being poorly trained regarding Geriatrics and ill equipped to assist Alzheimer patients and their families, either clinically or emotionally. The profession needs to be encouraged to address this situation.

- Co-ordinators working with families need good skills as facilitators and a commitment to make placements when needed

- Security for the patients is always a concern of staff. The institution as a whole needs encouragement to look for ways of improving security without reducing the patients' quality of life

- More resource centres for use by families and professionals, such as that created at Castleview - Wychwood Towers in Toronto, adjacent to the new Alzheimer's wing

- Readily available information about the disease for discussion with clients

- Funding for co-ordinated applied research that is not only pathological and neurological, but basic and practical

- Canadian research into epidemiology of Alzheimer's disease

C. NEEDS OF VOLUNTEERS WORKING WITH ALZHEIMER'S PATIENTS

Volunteers play an invaluable role in all social programs and can provide great support to families. However, working with demented patients is not easy, and those who do volunteer have needs that include:

- Careful screening, selection and training by Agencies recruiting and co-ordinating volunteers

- A clear understanding of the role and usefulness of volunteers in providing either friendly visiting or short-term respite care

- Support and acknowledgement, particularly for those volunteers who undertake to offer respite care in home settings, which is acknowledged to be stressful and, at times, very difficult

- Co-ordination of their services, since the client and family needs dependable respite care

- Encouragement to work with an established daycare project if home respite care is too great a responsibility

- Encouragement to seek creative ways of providing volunteer services for Alzheimer patients. For example, young mothers volunteering together in a day care centre for Alzheimer patients are encouraged to bring their small children who enjoy and accept the patients very well, as has been demonstrated in the Ward 9 - Senior Link daycare project in Toronto.

PART III

A REVIEW OF PROGRAMS AND RESOURCES

A review of programs and resources that could be used to meet the identified needs has been made by Council Members in their own communities across the province. Much of the following information relates to large population centres, such as Toronto, Ottawa, Sault Ste. Marie, and Brockville.

- The Ministry of Health Home Care Program provides chronic care for a limited time to families having members with Alzheimer's disease.

- The Ministry of Community and Social Services provides the Visiting Homemaker and Home Support Services Program, which has 80% provincial funding and 20% Municipal funding. This program is administered by Municipalities, who determine the needs through the Red Cross, V.O.N., or Visiting Homemaker Association, or agencies from the private sector. The program is needs tested and clients are asked to contribute if they can.

- Community Occupational Therapy Associates (COTA) in Toronto, under the Ministry of Health Home Care Program provides psychogeriatric services for the elderly, which includes assessment and co-ordination of services for seniors. 20% of 500 long-term care clients have Alzheimer's disease.

- Council is aware of Respite Care Programs available in Toronto, (S.P.R.I.N.T., Seneca Village, Ward 9 - Senior Link, Queen Elizabeth and Riverdale Hospitals, Sunnybrook and Baycrest Geriatric Centres, and some Metro Homes for the Aged.)

- Ottawa has two programs, one called "Day Away", a therapeutic daycare program, and a home assistance program. A more detailed description will be found in Appendix A.

- Brockville has a limited Home Care Program but no daycare

- Sault Ste. Marie has need for Respite Care Programs. Daycare is available at hospital, but on a limited basis. The Home Care Program is very active; two Nursing Homes and one Home for The Aged provide vacation care beds in the chronic care facilities

- Mount Forest area lacks home care services and respite care programs. Nursing Home beds are available for patients in advanced stages of disease

- Vacation respite care beds are available in some Homes for the Aged in rural Ontario and other larger centres; private nursing homes will also provide care.

- South Essex County enjoys a daycare program called "Outreach", which operates three days a week, is funded by the Ministry of Community and Social Services, and accepts Alzheimer patients.

- The Alzheimer Society of Ontario has an excellent series of information pamphlets available in English and French; funds are being sought to translate them into other languages.

- The Alzheimer Society also has an active volunteer program and provides self-help groups and educational seminars for the public; they are aware of the need to establish more chapters in smaller centres in the Province.

- Information materials prepared by the Alzheimer Society are shared with members and are available at public meetings; there is a need to reach caregiving families who are <u>not</u> aware of Alzheimer Society materials and activities.

- The Media is showing an increasing interest and awareness of Alzheimers Disease. Information about successful program designs, volunteerism and self help groups should be provided to the media, who can make the information available across the Province.

PART IV

RECOMMENDATIONS

The Ontario Advisory Council on Senior Citizens, respectfully submits the following recommendations in an endeavour to meet the needs of Alzheimer patients and those providing services and care for them.

- Reliable affordable day care, ideally having a therapeutic content, should be provided along with allied homecare assistance programs, in as many communities as possible. (See Appendix A for a report on the Ottawa demonstration project.) Existing agencies could be used to promote and administer smaller projects in outlying areas; additional provincial government resources will be required in this respect.

- Co-ordinated home care and home support services should be increased, to support the family in caring for Alzheimer patients at home. These services should include the provision of family counselling.

- The fee structure for Homes For the Aged and Nursing Homes requires overhauling, in order to recognise the different levels of nursing care required by clients, particularly Alzheimer patients, and to improve accountability.

- All institutions providing long term care for Alzheimer's patients, whether public or private sector, should be required to provide an established minimum ratio of nurses and nursing aides to patients.

- All private sector long term care institutions should be required to retain and make available to patients, their families and the staff, the counselling services of a professional social worker for not less than 24 hours per week per institution.

- District Health Councils should be asked to develop, with community agencies and workers, a model for monitoring projected availability of long term care

beds and identified Alzheimer patients moving through the stages of their disease. The objective would be to facilitate speedy and appropriate placement when required, thus avoiding penalising families who maintain the patient at home for as long as possible.

- In service training programs for all staff in long term care institutions should be required and the delivery of such programs should be monitored.

- The Ontario Medical Association and the College of Family Physicians of Canada should be asked to develop continuing education programs in gerontology and geriatrics, publishing as much literature as possible for their membership.

- Means of providing outlying areas of the Province with access to geriatric assessment teams are required. A schedule of consultations in Elderly Persons Centres, hospitals or Homes for the Aged would be one means of achieving this, using a small team of geriatricians and professionals from major teaching centres. As a useful learning experience, a limited number of health care students could be included on the team.

- Improved diagnostic and assessment tools should be developed for use by Physicians and other health care staff outside major cities, to include functional abilities as well as verbal, cognitive and neurological factors

- A model for Community related agencies to use in developing good volunteer training programs and implementing co-ordinated volunteer-resourced respite care programs, should be designed by the Ministry of Community and Social Services and made available to those seeking funding to establish respite daycare programs

- Agencies and service providers using volunteers to resource programs, should be allowed to build into their budgets an amount to provide transportation and support costs for their volunteers

- Volunteers providing transportation for clients should be paid a fixed amount/km. for distance driven

- The Government of Ontario should proceed as quickly as possible to implement protective Legislation to provide guardianship of the person as well as of property

- The Ministry of the Attorney General should be asked to make available to all levels of Police throughout the Province, specific information about Alzheimer's Disease. This should include a clear description of the confused stage of the illness when patients are inclined to wander and may come into Police care.

- The Government of Ontario should approach service clubs and, in particular, the Women's Institute which has province-wide representation in rural Ontario, to encourage these groups to work with the Alzheimer's Society in holding public meetings and providing information about Alzheimer's Disease.

- Alzheimer Societies should be encouraged to continue their excellent programs to disseminate information, at low cost to purchasers. Additional government funding to enable the material to be made available in languages other than English/French, should be provided at both the Federal and Provincial levels.

- Co-ordination of Research to provide substantive data based on Canadian experience should be sought through Health and Welfare Canada, to include all provincial jurisdictions.

- In co-operation with private Foundations, medical institutions and public benefactors, research should be directed toward diagnostic techniques, nursing care, family stress in caring for members suffering from Alzheimer's disease and the development of models in home support programs applicable in areas outside major teaching centres.

- The Ministry of Health should be encouraged to make available information on the Ministry's experience in the design and engineering of long term care facilities oriented toward accommodation for Alzheimer patients; this information would be of assistance to smaller communities contemplating project development.

ALZHEIMER'S DISEASE SUPPORT SERVICES, OTTAWA

(ORGANISED BY THE LOCAL ALZHEIMER SOCIETY)

Two main programs, operating in tandem, have been in existence since early 1985. They are the "Day Away" program which aims to maintain the client in the community for as long as possible, and the "Home Assistance" program which aims to optimise the client's functional competence at home.

The services are based on the Elizabeth Bruyere Health Centre which is housed in the former General Hospital and which was built a great many years ago. The area for use by the Alzheimer Society was reconditioned by the Society and its volunteers.

It should be underlined that assured financing was available only from April 1, 1985 to March 31, 1986. It may very well end at that time. In effect, it is a pilot project which it was hoped would serve as a role model for other communities. A recent independent detailed evaluation of its performance to December 1985, gave full marks for the work being carried out. It was acclaimed as the first of its kind in Canada and possibly in all of North America. In the interests of Alzheimer sufferers everywhere this important new approach should not be allowed to lapse. It represents a gleam of light in an otherwise sombre picture.

The current year's finances come basically from the Ministry of Community and Social Services ($100,000) for the "Day Away" program and from the Ontario Ministry of Health ($64,000) for the "Home Assistance" component. The Society itself came up with approximately $30,000 while other community charitable organizations provided special grants especially with start-up costs.

The program is staffed by professionals including a co-ordinator, a registered nurse, social worker, a registered nursing assistant (male), a family support person (psychologist), an occupational therapist and a recreologist. A number of these work only part-time. The volunteer component is very important and includes students from the local Community College as part of their field placement work.

No firm figures are available but it is estimated that there are from 3000 to 5000 persons suffering from Alzheimer's disease in Ottawa-Carleton, most of whom, though not all,

are older persons. In the first six months of its existence the program catered to 145 families at the Home Assistance Program and 50 clients in the Day Away Program in the first 6 months.

A local limousine service (Hill's Limousine) has very kindly accepted the main responsibility for transportation of clients. A specially designed van with a trained driver picks up the clients at home, conveys them to the centre in the morning and takes them home later in the day for a very nominal charge. It should be emphasised that the driver, who is always accompanied by a staff person, is well versed in the needs of his passengers.

DAY AWAY PROGRAM

This program provides respite for the caregiver and a social experience for the client. An interdisciplinary medical team designs an individual therapeutic care plan based on a comprehensive functional assessment. This will be made available to the staff of the facility when a client is admitted to long term care.

In amplification, the plan starts with a complete assessment in the home setting. If found suitable for entry to the program the client attends the centre one day a week. There, he or she will be involved in structured daily activities including: periods devoted to reinforcing basic living skills in grooming and hygiene and other tasks such as cooking and sewing in the case of women, or activities such as carpentering in the case of men; exercise classes; some socialization, and occasional outings.

The day's activities are run by two staff members and four volunteers with eight clients attending each day.

The clients contribution is $10.00 a day, which includes a hot lunch, snacks, and activity supplies.

HOME ASSISTANCE PROGRAM

The objective of this program is to optimise the client's functional competence in the home. This is done by endeavouring to improve the home environment for both client and care-giver by helping to develop strategies for home management. Functional, psychosocial and family burden assessments conducted in the client's home enable an individual habilitation plan to be worked out with family members and other service providers. The staff may make regular visits if required.

In practical terms the sufferer may get professional advice on how to adjust to the home environment involving feeding problems, sleeping difficulties, incontinence, grooming and clothing and so on. Care-givers are of course the key to all of this and are helped a great deal by the realization that someone else will share their problems in carrying on throughout "The Thirty-six Hour Day".

REFERRAL

Anyone in the community can make a referral to either program. It does not have to be made by a physician or other professional health worker.

VOLUNTEERS

Volunteers have been forthcoming in sufficient numbers to make a valuable contribution to these programs. The majority come from professional backgrounds, especially nursing, while others are motivated by family or other personal contact with Alzheimer's Disease.

Volunteers are put through a very careful process of selection before they are accepted. An extensive process of in-service training follows, which includes disease processes, physiology, personality traits etc.. A commitment is sought that the volunteer agree to serve one day a week for at least six months.

OUTREACH

An adjunct of the two main programs is the opportunity to provide educational and counselling services in the community. These are especially important in the three Homes For The Aged who accept Alzheimer's patients. (They have locked units.) Contact is also maintained with most of the other institutions serving the elderly.

Another development has been the recent formation of a community committee which as yet has no name but which is composed of a cross section of professionals interested in Alzheimer's Disease and who are employed in local institutions and agencies. They are fourteen in number and propose to concentrate on the needs of those with Dementia whether due to Alzheimer's or other causes.

Prepared by H. Hanmer
January 23, 1986

AN ANNOTATED BIBLIOGRAPHY OF

STUDIES AND ARTICLES

EXAMINED FOR THIS REPORT

1. Alzheimer's Disease: A scientific Guide for Health Practitioners: U.S. Department of Health and Human Services Pub. No. 81-2251 November 1980.

   - o Estimates that 600,000 to 1,200,000 Americans 65 years and older have Alzheimers.
   - o Alzheimer's disease is responsible for an estimated 100,000 to 120,000 deaths annually in U.S.A.
   - o Since it is recognised that the etiology, pathology and prognosis of Alzheimer's Disease is the same regardless of age of victim, AD is used to mean the illness for those younger or older than 65.
   - o AD ranked as 4th or 5th leading cause of death in U.S.A.

2. A consideration of statistical estimates related to Alzheimer's disease in Canada by Dr. Donald Morison Smith (unpublished).

- o Using 1/10 factor, this study indicates a Ontario experience of 66,000 to 120,000 sufferers of Alzheimer's Disease. The death rate is estimated to be 10,000 to 12,000 annually.

- o A more accurate occurrence is believed to be 170,000 patients in Canada having irreversible dementia.

- o Projects a 50% increase by turn of century.

COMMENTS

- o Both studies acknowledge that Alzheimer's Disease is often not given as primary cause of death; such cases may then be excluded from above statistics.

- o Similarly, most of the data having been drawn from deaths recorded by hospitals, the data may not include the deaths of many Alzheimer patients which occur in non hospital or institutional settings.

- o No reference is made to any Canadian Epidemiological studies related to Alzheimers; discussions with academic and medical staff have not uncovered the existence of any such study.

3. Alzheimer's Disease: Legal and Financial Concerns
AD Society for Metro Toronto, Inc. (Rev.Edit.)

- o A pamphlet pertaining to Ontario Law as of January 1984.

- o Provides very clear information in areas of Legal Rights and Responsibilities; Legal matters of driver's licences and wills; Financial matters and Institutionalisation.

4. Diagnostic Guidelines for Families: Alzheimer Society of Canada, Info. sheet #3. October 84.

   - o Information for the family to assist in assessment of evaluation and understanding of purpose of testing.

5. Who Can Help?: Alzheimer Society of Canada, Info. Sheet #1, October 84.

6. Brain Tissue Banks: Alzheimer Society of Canada, Info Sheet #2, October 84.

7. Pamphlets, flyers and bibliographies relating to Alzheimer's Disease published by Alzheimer Society for Metro Toronto.

COMMENT

- o The Alzheimer Society is the major publisher of information materials for the general public.

- o Small charges for materials assists with costs.

- o Materials are available at Conferences, Annual Meetings etc; no general mailings are undertaken other than to membership.

- o Some principal materials are available in English and French; translation to other languages is planned.

8. My Mother has Alzheimer's Disease: Dyanne B. Gibson Article in Chatelaine Magazine, October 83.

9. Is it Really Senility?: Robin Marantz Henig. condensed from Woman's Day, August 83, N.Y.

10. Alzheimer's Disease: Richard J. Wurtman
Reprint Scientific America, January 1985
Presents series of conceptual models under research testing.

11. Clinical Aspects of Alzheimer's Disease: Burton V. Reifler M.D. MPH published Clinical Review, October 83, Vol. 38, No. 10
A review of AD for practising physicians.

12. Learn about Alzheimer's Disease: David Rockman, President Montreal, Alzheimer Society, published Today's Health April/May 1984

13. Coping and Helping with Alzheimer's Disease: Writings in Gerontology series published by the National Advisory Council on Aging, Ottawa, January 1984. A discussion from the perspective of the impaired person, the family and the spouse, with information regarding institutionalization.

14. Toward a Better Understanding of the Home Care Program Published Community Health Matters, Summer 1985

15. Ontario Home Care Program Background Information published Ontario Ministry of Health, October 1985

16. Proposal for Sprint In-Home Respite Care Program submission by S.P.R.I.N.T. to Ontario Government for funding to establish pilot day respite care program in Toronto.

17. Elderly Residents in Ontario: Seniors Secretariat, 1985. A series of reports issued on the results of the USCO project.

18. Activities Report: Greenacres Home For the Aged, Newmarket. A survey of existing goal oriented activity programs within the institution, designed for patients with dementia.

19. Alive and Well at Wesley Hall: Dorothy H. Coons, published OAHA quarterly, July 85.
Based on presentation to 1985 Conference of Canadian Long Term Care Association in Quebec City,
Describing project for persons with severe memory loss having great difficulty living in a Home for the Aged.

20. Senior Citizens Secretariat Newsletter; Government of Nova Scotia #28, published November 85 - 4 articles related to Alzheimer's Disease.

21. The Gerontologist, published Gerontological Society of America. Vol.25, Number 6, December 1985 Project Renew: Development of a Volunteer Respite Care Program, F. Ellen Netting, Ph.D, ACSW and Ludell N. Kennedy, B.A.
Describes an at-home respite care program using trained volunteers to provide day and night care for frail elderly.

22. Dementia: A Family Problem by Kathy Gates published Gerontion, A Canadian Review of Geriatric Care, Jan/Feb 1986

23. A Program of Activities of Daily Living for the Cognitively Impaired, Gina Rohs published Gerontion Jan/Feb 1986

24. National Newsletter of Alzheimer Society of Canada, Vol.8. No. 4, October 1985

25. Annual Report 1984-85, Alzheimer Soceity

26. Long Term Care of the Elderly, August 1981 by P. Slotee, K. Rockwood and Duncan Roberts, Saskatchewan Health Status Survey of the Elderly, Report 1.

27. Alzheimer's Disease, A Family Information Handbook published Health & Welfare Canada March 1984. This useful handbook was prepared by the Alzheimers Society of Canada. First published 1982, it was rewritten in March 1984. The book provides information on the causes, symptoms, diagnosis, stages and ways of caring for an Alzheimer victim. It also discusses community resources, how to choose longterm care and legal issues.

28. The 36-Hour Day, Nancy L. Mace and Peter V. Rabins, MD, published John Hopkins University Press 1981, available through Alzheimers Society of Canada. Related to the American Health care system,. this is very supportive as well as informative paperback for families. It contains practical case management advice and techniques.

29. Alzheimer's Disease, Report of the Secretary's Task Force on Alzheimer's Disease, September 1984 U.S. Department of Health and Human Services, the Task Group, composed of 10 Agency and Program Heads from the U.S. Department of Health and Human Services, was asked to address issues around co-ordination of research and the means of applying such research to practical ways of enhancing life for Alzheimer patients. It provides Recommendations around Research in Epidemiology, Etiology, Diagnosis, Clinical Course, Treatment, The Family, Systems of Care, Research and Clinical Training and Information Dissemination with a special recommendation on finance.

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